Care partners' perceptions of amyloid-targeting therapy and treat-to-clearance for Alzheimer's disease in Japan: A qualitative study

Supplementary Material

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SUPPLEMENTAL FILE 1: INTERVIEW GUIDE

1. INTRODUCTION (3 MINS)

: Icebreaking, understanding of participants

① Age

② Relationship with the individual with Alzheimer's disease (AD) and family members living in household of the individual with AD

③ Occupation and hobbies of the individual with AD

④ Your occupation and hobbies

Include any changes in occupation and hobbies before and after the onset of the disease (e.g., retirement)

2. DIAGNOSIS (10 MINS)

: Secondary Objectives (burden among care partners), understanding of participants

① [The trigger for awareness of the disease]

・What prompted you to seek medical attention?

- What kind of unusual events (for either partner or individual with AD) occurred?

② [Visit to the physician]

・Did you go to any medical institutions or consultation centers before your present hospital? Why did you choose your present hospital?

- Source of information

③ [Examination]

・What kind of examinations have the individual with AD had at this facility?

・What impression do you have about the amyloid PET examination?

- Did you know about amyloid-β? If so, what?

④ [Diagnosis]

・What was the state of the individual with AD on hearing the diagnosis? How did you feel on hearing the diagnosis?

3. CHANGE IN DAILY LIFE (10 MINS)

: Secondary Objectives (burden among care partners)

・Has daily life changed since the individual with AD received their diagnosis of AD?

- Difficulties or worries about the individual with AD

・When and in what situations does the individual with AD need your support?

- (e.g., psychological support for anxiety, managing outings, banking, shopping)

4. TREATMENT AND PARTICIPATION OF THE CLINICAL TRIAL (10 MINS)

: Primary Objective, Secondary Objectives

(For partners of individuals with AD participating in the clinical trial of donanemab)

・Treatment received before participation in the clinical trial

- What kind of views and opinions do you/the individual with AD have about the treatment that you/they have received?

・History and reasons for participation in the clinical trial

- Were you or the individual with AD not satisfied with existing treatments?
- Did you or the individual with AD make the final decision to participate in the trial?

・Your views on participation of the individual with AD in the clinical trial

- How burden do you and the individual with AD feel about them receiving intravenous drip therapy?
- Are there any challenges about participating, such as commuting to hospital?

(For partners of individuals with AD who are not participating in the clinical trial of donanemab)

・What treatment is the individual with AD currently receiving?

- What views and opinions do you and the individual with AD have about treatment?

・What do you and the individual with AD think about their current treatment?

- Drug treatment: is there any burden related to taking medication or outpatient visits?
- What are your views on non-drug treatments (e.g., rehabilitation, exercise therapy)?

・How satisfied are you with the current treatment of dementia?

Please express your satisfaction as a score out of 10, where 10 is the highest possible score.

- What do you think could be done to improve this score?

5. TREAT-TO-CLEARANCE (25 MINS)

: Primary Objective, Secondary Objectives

[Screen sharing] Present data ("New Drugs for AD in Development")

(Moderator reads the text)

Description:

① AD is closely related to the accumulation of amyloid-β protein in the brain

② New drugs were developed to remove the accumulated amyloid-β in the brain

③ Removal of amyloid-β may slow the progression of AD

④ Treatment with this drug is given by a specialist, with one infusion every 4 weeks

⑤ If PET examinations show that amyloid-β has been removed, treatment with infusions is stopped. Individuals with AD need regular visits after stopping infusions.

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① [Impression]

・(For partners of individuals with AD who have not taken part in the clinical trial of donanemab) Is there anything there that you didn't already know?

・What is your impression of drugs with these characteristics?

② [Perceptions of stopping treatment]

・What do you think about the idea of "treatment by infusions is considered stopped" in the description?

・If your individual with AD is able to stop the infusion treatment, what effects do you think you would see next?

[Screen sharing] Impact of stopping infusion treatment

※show the PowerPoint materials

A) Number of visits (for treatment)

B) Waiting time at the hospital

C) Cost of treatment

D) Identifying that the causative agent of AD, amyloid-β protein, has been removed

E) Periodic MRI testing for checks for adverse drug reactions

・For each item: what effects would it have on your life? How do you feel about this?

・Relative comparison: Which item do you think would have the biggest effect on your life?

・Can you foresee any other effects?

6. CLOSING (2 MINS)

・Finally, do you have any comments about anything we have covered in this interview, or anything you would like to add?

Supplemental file 2: Representative narratives of the themes

Broad categories	Theme	Sub-theme	Representative narrative
1_ Thoughts regarding therapy	Expectations for improvement of cognition and function by Aβ removal		(When asked about impressions of the therapy) "(Omitted) If it (amyloid beta) can be removed over a certain period of time and the symptoms of dementia can be alleviated, then I think that would be good. " (Omitted) "For example, up until now, and this is true for the current medications as well, on TV they're always saying that dementia drugs are not reliable cures, so I think that it will probably continue to build up, and I wonder how long it will take for a sufficient amount of the amyloid beta to be completely removed. I wonder how long it will take for the symptoms of dementia to differ or change. " (Woman in her 50s) （治療についての印象を聞かれ）『（前略）一定期間でそれ（アミロイドβ）が取り除けて、認知症の症状が軽くなるのであれば、そこはいいなと思います。』（中略）『認知症のお薬は、例えば今まで、今のお薬に関してもそうですけど、安全に治るものじゃないよっていうのがテレビとかでもよく言ってるんで、なのでやっぱりまたそれがこう溜まっていくんだろうなっていうのも思いますし、まあ完全にアミロイドβが十分に取り除かれるっていうのがどのくらいなのかなって。どのくらいで認知症の症状が違ってくる、変わってくるのかなっていう疑問はあります。』（50 代女性）
	Sense of reassurance that the removal of Aβ can be confirmed		"(Omitted) I don't think the person has said it out loud, but I'm sure the person is worried about what will happen if the person's condition continues to progress, so when the person gets told the amyloid beta has been removed (through treatment) and the infusion is finished, although it does not alleviate one of the person's concerns, I think the person will be able to put it aside for a while, and I think that ought to make the person feel a little more at ease." (Woman in her 30s) 『（前略）多分本人も口にはしてない、このまま進行したらどうしようって気持ちがきっとある中で、なので（治療で）アミロイドβが取り除けましたよ、点滴終了しましたよってなると、ひとつの不安は多少解消はされないけど、ちょっと横に置いておくことができるのかなと思うので、本人の気持ちは少し楽になるのかなと思いますね。』（30 代女性）

	Concerns about high cost of treatment		(When asked about the care partner's image of out-of-pocket medical expenses) "(Omitted) In the end, it depends on how much you have to pay out of your own pocket and how much you'll get back, but expensive medical care is still expensive. (Omitted) So, I don't know, I have no idea what the market price is, but if it's the list price, or if insurance doesn't cover it, I guess it would be several hundred thousand yen. They were saying several million per year, right? Did they say several million? (Omitted) (Laughs) That's still a lot, right? For an ordinary person. " (Man in his 50s) （治療費の自己負担のイメージを聞かれ）『（前略）結局、それの自己負担額がなんぼで高額医療だからなんぼ返ってくるんでしょうけど、高いのは高いですよね。（中略）だから、わかりませんよ、もう相場っていうのが全くわからないんですけど、定価というか保険が利かないんだったら数十万円、なのかな。年間でも数百万と言ってましたよね。何百万って言ってましたっけ？（中略）（笑）それでも大きいですよね。普通の人にとっては。』（50 代男性）
	Concern about adverse drug reaction		(When asked the care partner's thoughts and interests regarding the therapy) "(Omitted) I had heard before that there were side effects such as bleeding when the amyloid beta is removed, so I was worried that something like that would happen to the person... At that time, the person had been living alone forever, so if something like that were to happen at night, wow, I thought that would be a problem. " (Man in his 50s) （治療に関する感想や興味を聞かれ）『（前略）アミロイドβが取り除かれるときの出血があるとか、そういう副作用があるというのは以前聞きましたので、まあ、本人にそういう…、その頃はずっと一人暮らしだったんで、そういうのが夜間に起こったりしてたら、え～、困るなとは思ってました。』（50 代男性）

2_ Treat to clearance	Increase of personal time through a reduction in the frequency of examinations and outpatient visits		"Well, yeah, that's right. Since I don't have to take the person to the hospital anymore, well, I guess I can at least do a little more volunteering. (omitted) I think it has increased. Well, when I don't have to go (to the hospital), that means I can go volunteer. (Omitted)." (Woman in her 40s) 『まあ、あの～、そうですね。通院しなくていいから、まあボランティアにもう少しいけるかなっていうぐらいですかね。（中略）増えたと思います。あの～、（病院に）行かなくていいときには、ボランティアに行けるので。うん、そうです。はい。』（40 代女性）“It hasn’t changed that much, but since we’ve been going to outpatient visits at that hospital more often, I’ve had to take time off work or go home earlier more often." (Woman in her 50s) 『そんなに大きくは変わってはないんですけど、やっぱり、あの病院の通院が増えましたので、ちょっと仕事を休ませていただいたりとか、早く帰らせてもらったりっていうのは増えましたね。』（50 代女性）
	Willingness to continue examination and outpatient visits even after stopping treatment	Concerns about Aβ re-accumulation and the progression of symptoms	(When asked about concerns regarding stopping treatment) "Yes, I have some. I'm also worried that (the person's) condition will end up progressing again suddenly. Even if the drug can slow down the progression, and let's say it reduces the amyloid beta, my worry is something like, if the person stops taking it, won't the disease come right back again? (Omitted) In any case, I am also worried that things might progress suddenly, and drastically." (Woman in her 50s) （投与完了による不安があるか問われて）『ああ、ありますね。また一気に進行してしまうのではないかなっていう不安もあります。お薬で進行を遅らせるというか、アミロイドβが減っていったのに、やっぱりやめるとまた復活していくんじゃないかなっていうような心配があります。（中略）でも一気にガタッと進行したりしないかなという心配もあります。』（50 代女性）

		The desire to maintain a connection with medical care	(When asked about the impact of stopping treatment) 'It's nice not having to come, but, well, I'm still kind of worried. It's feel like being thrown out, something like being left to fend for ourselves. (Omitted) If you want to say that we worked hard here, that's fine, yes. I don't think it's like that, so in the end, when it's over, it's over, and I feel really lonely, you know? Yes." (Woman in her 50s) （投与完了による影響を問われて）『来なくていいことは楽ですけど、やっぱり、あの～、なんか不安ですね、やっぱり。なんか放り投げられたような、放り出されたようなっていうか。（中略）ここで頑張りましたって言うんだったら、全然いいんですけど、はい。そういうものではないと思っているので、やっぱり終わったら終わったで、すごく心細くなりますね。はい。』（50 代女性） (Asked about the requests to the hospital after stopping treatment) "Let me think. For example, I think there are some doctors who just say, 'OK we're done,' and then it's over, but if they can make me feel like I can get some aftercare (laughs), something like saying, 'Please come and talk to us about anything,' then that eases some of my anxiety. I think that might make me feel better." (Woman in her 50s) (投与完了後の病院への要望を問われて)『そうですね。例えば、あの～、もう終わりましたで終わる先生もおられると思うんだけど、「何かあったら何でも相談してください」とか、そういうアフターケア(笑)をしてもらえるんだっていう気持ちをこっちに持たせてくれるような感じだと、少し不安は取れる。軽くなるんじゃないかなって思います。』（50 代女性）
	A sense of liberty by reducing waiting time of treatment		"Yes that's right. For sure. I think it's probably good that the time (spent waiting for the intravenous infusion) will be shorter. It sounds easy. (When asked how it makes things easier) Well, in our case, our dog is a bit senile (laughs), so when he has to go to the bathroom sometimes, you know, that's it. So, you know, if it's going really long I do get a bit worried about (the dog) going to the bathroom... (bitter smile), so there' that, yeah. It's fine when my husband is there though. Yes." (Woman in her 40s) 『そうですね。そうですね。（点滴を待つ）時間が短くなるのは、いいかなと思います。楽そうですね。（どういう風に楽になるかを聞かれて）ん～っと、うちの場合だと、ちょっと犬がシニアで(苦笑)、ちょっとあのトイレの時間があって、そうなんですよ。だからあの～、あんまり長い時間だと、ち

			ょっとトイレどうしようっていう心配が…（苦笑）あるので、はい。主人がいるときならいいんですけど。はい。』（40 代女性）
	No alteration to the current lifestyle even after stopping treatment		(When asked how life will change due to stopping treatment) "... (thinks for a moment) I don't think it will change much at all (laughs). (Omitted) Well, you know, how do you say, normally, uh, you have to go to the hospital for outpatient visits on a regular basis. Which means, well, I go there regularly for checkups, which is what I've been doing up until now. Also, if my mother, in that house, the person's symptoms or what you might call the person's behavior patterns can be improved, I think life will probably change. But if the person's current state is just maintained, it will be the same as before. Yeah, I'll probably be getting annoyed about the same things (laughs). So the quality of life itself won't get any worse. Yeah. So somehow they managed to stop it at its present state. Yeah, with things going like this, I feel like we'll have to stick it out with my mom, for a long time. I don't know. If it actually happened, there may be things that get easier or better (laughs), but it's still just hypothetical, so I can't think much beyond that, not until it actually happens." (Man in his 50s) （投与完了により生活がどのように変わるか問われて）『…（考え込む）ほとんど変わらないと思います（笑）。（中略）えーと、そのー、どうなの、普通の、えーと、定期的な通院になりますっていうのありますよね。ということは、まあ、定期的にそちらの方に出て診察、それはもう今までしてきたことなんで。あとその家での母親の症状というか行動パターンというのが、改善されるのなら、生活は多分変わると思います。でも現状維持だったら、今までと変わらないですね。うん、多分同じとこで多分イラッとするだろうし（笑）。だから生活の質自体はこれ以上悪くならない。うん。現状維持で何とか食い止めれたな。うん、このままだから、長いことね、おかあちゃんと付き合っていかないといけないなっていう感じですよね。わからないですよ、実際そうなったら何か、何かしら楽になったり、よかったなって思うことがあるのかもしれないんですけど（笑）、まだ仮定なんで、そこまでしか考えられないですね、実際になってみないと。』（50 代男性）

	Relief about temporary cost elimination associated with stopping treatment		(When asked about the impact of no longer incurring costs after stopping treatment) "Well, having an end to things is better than having to keep going to the hospital until you die, so that does have an impact." (Woman in her 60s) （投与完了後に費用がかからなくなることへの影響を問われて）『まあ、ずっと死ぬまで通院しなきゃいけないいうよりも、終わりになった方が、それは影響があります。』（60 代女性）
3_ Burdens of support	Expressing anger towards people with AD during conversations, despite recognizing their dementia		(When asked if the care partner's relationship or interaction has changed since the person with dementia developed the disease) "Hmm, we don't really talk...I mean, we don't talk much, or rather, when we talk or something and the person replies with in a brusque manner, it bothers me, so even though I don't mean to be overly helpful or intrusive, it still bothers me, so when I say things like, 'Oh, Dad, do it like this,' or 'It goes like this, not like that,' the person gets very, like, sensitive about being fussed with so much, and, um, the person tends to get angry. (Omitted) I also feel that this might be due to the disease. " (Omitted) (When asked what is stressing the care partner out right now) "Ah, well... Umm, it's difficult to have a normal conversation, or, well, my husband is a little careless because of the person's position, and well, I don't mean to point it out forcefully, but do I want the person to be more careful, so I say, 'You should have done it like this,' and then, um, I think my husband feels like the person has been pricked with a needle, and so the person replies in a fairly angry tone. (Omitted) So, even for me, things I say with good intentions are often taken maliciously, and so now I strongly feel that it's better not to speak at all if that's the case. (Omitted) Well, I have to say the important things, but, well, it's really difficult right now to have a nice, friendly conversation. (Omitted) That's stressful, or I guess you could say, it makes me sad." (Woman in her 80s) （当事者が疾患になった以降関係性や関わり方が変わったかと問われて）『ん〜、あんまり会話…、会話がないっていうか、お話、なんか話ししてもつっけんどんな返事で返ってくると、あの〜、そんなにうるさく世話焼いてるつもりはなくても、あの気になるから、「あ、お父さんこうですよ」とか、「こうだこうじゃないの」とかっていうことを言うと、世話焼かれるのがとってもなんか敏感で、あの〜、怒ってくるところがありますので。（中略）それは病気のせいかなっていうところも感じます。』（中

			略）（今ストレスに感じていることを問われて）『ああ、それはね。あの～、普通の会話がなかなかできないっていうか、まあ、どうしても立場的になんかあの～、ちょっと主人の方になんかちょっとうっかりがあって私がそれをね、あの、強く指摘するわけではないんだけれど、あのちょっと気をつけてもらいたいと思うから、「こうだったんだよ」って言うと、それがもうなんか、あの～、主人には針に刺されたような気分なんでしょうね、そうすると結構ね、怒り口調で返ってくるんです。（中略）なので、私もね、良かれと思って言ったことが悪意に取られることもしょっちゅうですし、あれだったらもうしゃべらないほうがいいなっていう思いが今は強いです。（中略）大事なことは、まあ、言わなきゃいけないんですけど、あの～、だから和やかないい会話っていうのが、今はとっても難しい。（中略）それがストレスっていうか、悲しいですね。』（80 代女性） (When asked if the care partner feels any stress from supporting the person with dementia for so long) "Well, I guess I do. I guess I get asked the same thing over and over again, and even though I know I shouldn't be, it does make me a little angry sometimes. As you might expect. Yeah. " (Man in his 40s)(当事者のサポートをずっとしていて、何かストレスは感じられることはあるか、と問われて）『まあ、やっぱりそうですね。やっぱり同じこと何回も聞かれるんで、あの～、ちょっといけんのですけど、ちょっと自分の中ではちょっと腹が立つようなこともあったりはしますね。やっぱり。うん。』（40 代男性）

	Increased responsibilities in daily life	The burden of accompanying people with AD to their outpatient visits	(When asked about accompanying the person to outpatient visits for medical examinations) "Ah, now that I've quit my job it's not as much of a burden, but when I was working I still had to take time off, and some days it would take a whole day, with an IV in the morning, a quick lunch in between, and then psychological testing in the afternoon. No, no, no, I think the psychological test came first and then the IV in the afternoon. Anyway, the psychological testing would take up a whole day, so I just waited inside the hospital the whole time. So, of course, the constraints on my time were kind of tough, and taking time off from work, taking off once every four weeks, since I didn't tell anyone about it, I was always wondering how I was going get time off, you know? But really, once every four weeks comes quick, and once every three months takes an entire day, so there were time constraints, which thought were pretty hard when I was working. " (Woman in her 50s) （診察のために一緒に通院の付き添いをしていたことについて問われて）『ああ～、今仕事を辞めてしまってからは、そんなに負担ではないんですけど、やっぱり仕事しているときは、やっぱお休みもらわないといけないし、丸 1 日かかる日も、やっぱり午前中に点滴して、で、間にちょっとお昼を摂って、午後から心理検査だったかな。違う、違う、違う、心理検査を先にして午後から点滴でしたかね。なんかとにかく 1 日心理検査があるともう丸 1 日かかっちゃうので、ずっと病院の中で待ってたんです。なのでやっぱり、その拘束はちょっとしんどかったし、自分で会社を休むのも 4 週間に 1 回休むのも、やっぱり言ってない分、ちょっとどうやって休もうみたいな感じでしんどかったし、そうですね、やっぱ 4 週間に 1 回っていうのは結構早いし、3 ヶ月に 1 回は丸 1 日かかるから、ちょっと拘束時間もあって、まあ、ちょっと仕事をしているときはきついなって思いました。』（50 代女性）

		Increased need for managing the safety of the people with AD	(When asked if there was anything that troubled the care partner as the care partner watched the person's condition as the disease progresses) "(Omitted) Well, there were a few times when it got a little dangerous letting the person handle flames, you know, like burners in the kitchen, so we changed to an induction heater and also changed the bath to something simpler, whereas before it was gas. (Omitted) After all, it felt a little dangerous. I've made changes to make it as easy as possible so that even my mother could do it, but it's still getting more and more difficult for the person. Yeah. Even when I tell the person, "Press here" to set the timer for the bath, you bet, the person can usually do it, but sometimes, as you might expect, the person can't, and instead end up doing something weird, (omitted)." (Man in his 50s) （症状が進行する様子を見ていて何かとまどうことがあるかと問われて）『（前略）まあ、火とかを扱うのも、ね、あのキッチン、火とか扱うのも、やっぱりちょっと危ないなっていうときは何回かあったんで、それももう電磁調理器に変えたり、お風呂もなんかも簡単なね（中略）前はガスだったんですね。（中略）やっぱりちょっと危ないなっていうのがあって。できるだけ簡単にうちの母親でもできるかなっていうのを変えたんですけど、やっぱりそれでもだんだん難しくはなってきてますよね。うん。お風呂の予約をするのも「ここを押すんで」って言っても、やっぱり、大体できるんですけど、たまにやっぱできなくてなんか変なことしとったり、（後略）』（50 代男性）
		Taking over a role originally performed by people with AD	"As for shopping, well, until just two or three years ago, I used to go every now and then. I took the person with me, and we did that shopping, you know. But that, well, the person can't cook like the person used to, so we don't go shopping much anymore. But for better or worse, I used to cook, and I worked at that restaurant as a regular cook, so it was no big deal when the person told me the person couldn't cook anymore, and I just said, 'Well, I'll cook,' and I've been cooking ever since. As for shopping, it feels like I do most of it. " (Man in his 50s) 『買い物はね、それこそもう 2、3 年前までは、ちょこちょこは行ってたんです。私は連れて行って、あの買い物しとったんだったんですけど。それはね、なんかもう、以前のようにその料理もできなくなって、だからもう買い物にもあんまりもう、行かなくなっちゃって。でも幸か不幸か、私は昔、料理しとったんで、あのお店で普通に働いて料理作っとったんで、だから別に、そう言われて料理作らなくな

			ったから、ほんならワシが作るわ、でもう、私がもうずっとずっと作って。買い物も私がほぼほぼ行って、ていう感じです。』（50 代男性）
	Reduction of personal time for hobbies, work, and other activities		（When asked if the care partner is able to enjoy hobbies as much as before）"Hmm, not really, not as much as before. So, my personal time for hobbies has significantly decreased. And, I was originally a complete night owl, but my nocturnal lifestyle has gotten even worse. This is because I've found that I can't really control my own time unless I'm absolutely, completely by myself. So, it's only after my wife goes to bed that I finally get some alone time. That's when I watch the sports videos I've recorded, or just casually read a book – essentially, it's my me time. And that me time ends up being in the middle of the night. I'm actually a bit worried myself that I'd lose my balance without that time, so that's how I manage it."(Man in his 80s)（趣味が以前のようにできているか聞かれて） 『ん〜、まあ、そこまでは。だから、自分自身もやっぱりそういう、かなり減ってきてますね。どうしても。それに、まあ、ちょっと実は元々もう完全な夜型だったんですが、夜型の生活がまた一層ひどくなってきまして、というのは、やっぱり実質的に 1 人に、完全に自分が 1 人にならないとコントロールできなくなる可能性があるので、え〜、妻が寝てから、それからやっと 1 人になって、そのときに先ほど言ったスポーツビデオで録っていたものを見るとか、本を何となく読むとか、要するに 1 人の時間ですね。その 1 人の時間は完全に夜中になっちゃいますから、まあ、その時間がないとちょっとバランスが取れなくなっちゃうのが自分でも心配して、そんなふうにしています。』（80 代男性）(When asked if there have been any changes in the care partner's life since the person with dementia was diagnosed with the disease) "(Omitted) There is a medical exam about once a month, and on top of that there are the PET scans once every six months, so I have had a few more opportunities to take time off work, and, how do I put it, I can't devote all my time off to myself--some of it has changed, into something like time for my mother. (Remainder omitted)" (Omitted) (When asked how the care partner spent the care partner's time before the person with dementia was afflicted by the disease) "Not on anything major (laughs), but I think I would do stuff like going shopping with my family and spending time doing things I liked. But none of it was really all that important, you know. (Omitted) Yes. I do things like go shopping with my kids, window shopping kind of stuff, things like that."

			(Woman in her 50s)（当事者が疾患になってからご自身の生活に何か変化があったかと問われて）『（前略）月 1 回程度は受診ということになりますし、半年に 1 回はそれプラス PET の検査があったりとかするので、仕事を休む機会がちょっと増えたのと、なんですかね、休みを全て自分の時間に充てられないというか、母のための時間というふうなことにちょっと一部変わっていったので。（後略）』（中略） （当事者が疾患に罹患するまではどのように自分の時間を使っていたかと問われて）『大したことはないんですけれども（笑）、家族と買い物行ったりですとか、好きなことに時間を費やしたりとかはしていたかなとは思います。けれどもそんな大したことではないですけど。（中略）はい。子供と一緒に何か買い物行ったりですとか、ウインドショッピングとかそんな感じです。』（50 代女性）
	Anxiety regarding the future progression of symptoms		(When asked what the care partner feels is difficult about providing care to the person with dementia) "I think it's about how much, well, how much care I should provide. Right now I'm providing all the care, so I'm worried about how much assistance I can really provide, and whether I can do it all at home. I am worried whether I can care for the person at home (laughs). How much care can I give? Others are telling me, wouldn't it be better to put the person in a nursing home? People say things like that, but because I work in a nursing home facility myself, my main thought is that it'd be a pity to put the person into a facility. However, I think there are limits to the care that can be provided at home, and I'm not sure just how far that can go. I would like to care for the person at home until the end, but I'm not really sure that's possible. That's what I'm worried about right now. " (Omitted) (When asked what will be difficult about providing care at home) "I think the biggest difficulty is excretion. Otherwise, I've been doing things knowing that there isn't anything that can be done about the situation, so it's fine (laughs). I do think the excretion part is a bit tough, though. Since the person goes to the bathroom so often. Even if it's me that has to go to the bathroom that many times in the middle of the night, I start to get annoyed, so that's what I'm a little worried about right now (laughs)." (Woman in her 50s) （当事者の介助の難しさはどういうところに感じられるかと問われて）『やっぱりどこまで、その、介護をどこまで介護したらいいのかなっていう、本当に今全部介助してるので、本当にどこまで介助、家でできるのかなとかって、その不安ですよね。家で看れる不安（笑）。どこまで看れる？周りの人がも

			う施設入れたらいいんじゃない？って感じで言われるけど、やっぱり施設に入れるって、私も施設で働いているから、かわいそうっていうのが先に立つ。でも家で看れる限界もあるんだろうなっていう、その見極めがちょっと今どこまでなら。できれば最期まで家で看てあげたいけど、やはりどうなのかなって。そこが今不安です。』（中略） （自宅での介助でどういうところが難しくなりそうかと問われて）『やっぱり排泄面が一番大きいです。あとは別にそんなに仕方ないのかなって感じで今までやってきたので大丈夫なんです（笑）。排泄面だけはちょっとやっぱり厳しいのかなって。トイレが近いので。自分の体もそこまで夜中に何回もトイレいくと、ちょっとこっちもイラっとするので、そこがちょっと今不安なところ（笑）。』（50 代女性）
	Distress caused by witnessing the progression of symptoms		(When asked if there is anything difficult or worrying about interacting so closely with the person with dementia) "(Omitted) The fact that it doesn't get better. It gradually progresses, and well, that part is pretty tough. To watch it happen. (Omitted) Because I knew the person when the person was healthy. (Omitted) It's only a little at a time, but I can tell it's progressing." (Man in his 70s)（当事者のそばで接していて難しいと感じることや悩まれることはあるかと問われて）『ん～、まあ、よくならないですからね。少しずつ進行してるんで、まあ、そのへんは辛いですね。見てると。（中略）元気なときを知っているから。（中略）少しずつですが、進行してるなと。』（70 代男性）
	Poor understanding of dementia among healthcare providers, friends, family, and the care partner themself		"(Omitted) Well, the current doctor my mother is seeing, the doctor at the hospital where the person gets the person's medication from the Internal Medicine department, I have known that doctor for a long time, so, um, I asked the doctor, 'Should the person go to the hospital? For this dementia, you know?' And when I said that, the doctor said, 'If you go to the hospital for that, that'll be the end of things, so don't worry about going.' (laughs)." (Woman in her 50s) 『（前略）あの～、母が今通っている主治医、内科のお薬もらっている病院で先生に、そこの先生ももう長い付き合いなので、あの～、「病院に先生行った方がいいですか？こういう認知症の」って言ったら、「そんなもん病院行ったらもうおしまいやから行かんでよろしい」って言われて(笑)。』（50 代女

			性） "That's what the hospital told me (when the doctor suspected mild cognitive impairment), so I said, 'Maybe there's something we can do about it by giving the person some medicine or something.'(Omitted) Well, once the person starts taking medication and gets diagnosed with full-blown dementia, the person can't drive a car, or does a bunch of other things, so, the person's actions, I figured it's better for us to provide the person with stimulation, while doing a variety of activities. So, well, I took that suggestion, and decided to do that, and then went back for another MRI six months later." (Woman in her 70s) 『病院の方がそういう話（軽度認知障害の疑いありと伝えられた）だったので、「何か薬とか飲んでどうにかなりませんかね」っていうのを言ったんですけど。（中略）あの〜、薬を飲んでしまって完全に認知症というふうに診断名がつくと、車も運転できなくなるし、いろんなことが狭まってしまうので、行動が、それよりいろんなことをしながら刺激を与えていく形にしていった方がいいという。あの、なに、サジェスチョンをいただいて、それでそうすることにして、半年後にまた MRI を撮りに行きました。』（70 代女性）